

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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## **Aims and Scope**

*HIV Nursing* has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

*HIV Nursing* is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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# Partnerships in practice

Pauline Jelliman

CNS HIV/AIDS, Liverpool Community Health, UK

This issue's theme is 'Community and collaboration', particularly appropriate with conference just around the corner. We all want to see healthcare professionals and their allies working together as constructively as possible ... and upping their game in terms of anticipating and meeting patient needs. Equally, the individuals, families and groups who access services as patients need more than ever to be informed and empowered to get the best outcome possible. This has never been more keenly felt than in today's climate, where squeezed budgets mean the stakes are higher than ever.

Diane Exley and Kate Cernik set out the governing principles by which their general practice aims to offer the best possible service to people living with HIV, with the emphasis very much on continuity, adaptability ... and above all being approachable. My contribution looks at links between gender-based violence and HIV, an issue currently in the public eye following a recent feasibility study to explore the application of international research to the UK setting. Let us hope that we soon hear more on this subject.

Michelle Croston relates the outcomes from her project to devise a communication training study day for HIV nurses. The response from participants was certainly positive, and Michelle reminds us that

we need to keep an open mind: just because we have been doing something a long time does not mean that we cannot improve our performance!

Jacqueline Morris and Denise Davenport have distilled for us the key principles of an effective MDT approach. Their review is set against the backdrop of a complex patient case study by which they determined MDT efficacy and outcome, and which illustrates their points very clearly.

Agatha Benyera-Mararike has contributed a summary of her extensive research project into why migrant African women find it helpful to receive counselling that has cultural relevance to them, as opposed to classical western counselling. Meanwhile, Juliet Bennett takes us through the issues and arguments of a 'cure' for HIV, explaining why there's more to it than meets the eye – and why we will all be keeping our feet on the ground for the time being.

If you are heading to conference this year, we look forward to seeing you there. Please keep in touch and let us know what you would like to see in your journal, or consider making a contribution yourself. More information is available on our website.

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## Care tactics: serving diverse needs in general practice

Diane Exley<sup>1</sup> and Kate Cernik<sup>2</sup>

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### Background

Brownlow Health is an inner-city GP practice in Liverpool with a diverse population of approximately 28,000 patients including a large student group, asylum seekers, the homeless, patients with drug and alcohol problems and sex workers.

The practice offers a range of services providing specialised care, including outreach homeless services, outreach student services, plus hepatitis C treatment, weight management, sexual health, alcohol outreach and substance misuse services.

**'We believe that it is important to normalise HIV testing within a GP setting'**

This article describes our approach to HIV care, with brief examples (Panel 1), and explores the opportunities and challenges in managing this group of patients.

### HIV services offered

Fifty HIV-positive patients are registered with the practice. They include sex workers, drug- and alcohol-dependent patients, students and the general inner-city population.

Our multidisciplinary team offers screening and diagnosis, referral, education, health promotion, liaison, coordination and monitoring. Screening is provided at the point of contact wherever possible,

## Panel 1: Case studies and chosen strategies

### 19-year-old female sex worker

Screened in late-night practice session for sex workers. Young child living with her. Struggled to come to terms with diagnosis amid increasing chaos, mainly alcohol-related. Continued working. Liaison initiated between public health, Community HIV Team, family and drug/alcohol services to ensure appropriate management.

### Newly diagnosed student

Diagnosed in Ireland, just before starting university. Ongoing support initiated, relating to new diagnosis and new student life and linking into hospital clinic. Liaison with university departments requested and put in place.

### 30-year-old gentleman

Employed full time in inner city. Poor compliance followed by decision to stop medication altogether. Multiple physical and psychological symptoms. Restarted medication, with side effects. Difficult relationship with hospital, plus work and family issues. Regular follow-up arranged with named doctor, plus community/hospital liaison.

usually by venous blood sample but sometimes by spot testing. This often takes place in outreach settings, targeting at-risk populations. However, we believe that it is an important principle to normalise HIV testing within a GP setting and that clinicians need a high index of suspicion in many routine primary care presentations.

As a training practice, we are involved in medical student communication skills training. The key to successful screening is demonstrating appropriate attitudes, and being friendly and approachable. This hopefully instils confidence, enabling the patient to trust the clinician to manage and follow up screening appropriately and sensitively. In addition, it is important to have sound systems in place to follow up individuals and to be flexible in terms of delivering this service.

## Primary care approach

Patient support is clearly crucial at the point of a positive diagnosis, and our systems are set up to allow flexibility in how initial contact is made. This may be within the surgery or in outreach settings using a skill-mix of clinicians. We are very fortunate to have the help of Liverpool's Community HIV Team in some cases, when the process of referral and support is particularly complex. There is always a safety net of follow-up review with the GP, as sometimes onward referral is difficult or unacceptable to the patient.

**'The practice and its staff provide a stable, long-term platform that offers continuity of care'**

As a practice we also liaise with public health, particularly where the individual continues risky behaviour after diagnosis. Health visitors, district nurses, social services, as well as family or close contacts (eg, hostel staff),

may need to know the diagnosis, in order to offer support to patients or their families. There are also occasions where coordination of teams and case

conferences are required – again, links with the Community HIV Team prove vital in these situations.

Health promotion takes place through outreach in hostels, day centres and university settings, as well as via a webpage, on Twitter and Facebook, and in our waiting room. Educational events are coordinated for groups, eg, voluntary sector (hostel staff), GPs and nurses, as well as our practice team and neighbourhood.

We have also been involved in researching point-of-care testing in the community.

## Continuity and support

A key GP role is monitoring and review. We can deal with physical and mental health and wellbeing, sexual health, long-term condition monitoring and medication reviews. This is generally done on an ad hoc basis and it is in this area that primary care has the greatest potential to make a difference. The GP practice and its staff provide a stable, long-term platform that offers continuity of care to see the patient through periods of illness, life events and health changes arising from the ageing process.

HIV is a long-term condition, and as such primary care is the ideal place to monitor stable patients. Although there will always be the need for specialist involvement, a shared-care model can fit well with this condition.

The challenge is to provide personalised, holistic care in a setting suitable to the patient, with clinicians appropriately skilled to manage needs. Communication between teams can be difficult in an increasingly busy NHS but is essential for best management outcomes.

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# Gender-based violence and HIV: associations and interventions

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## Introduction

For women with past or current exposure to gender-based violence (GBV), its outcomes for health and wellbeing are many and complex – impacting on work and study, home and family, health and children's health. The way that HIV and GBV link and overlap has long been under discussion and the hope is that more UK-specific research and action will soon be forthcoming.

### *The cost*

Women's Aid UK describes the following outcomes of GBV, for individuals and their families [1]:

- loss of opportunity
- time off work or study
- long-term impact on financial security and career
- loss of income or work
- emotional/psychological effects such as anxiety, depression or lowered sense of self-worth
- poor health
- physical injury or ongoing impairment
- miscarriage or stillbirth
- death (in the UK, two women per week)
- isolation from family/friends
- homelessness

### *The profile*

The traditional perception of women as survivors of violence from men is an inaccurate generalisation, especially in the context of HIV among vulnerable groups such as sex workers, injecting drug users, MSM and transgender people [2]. Among these groups, the picture is rarely clear cut and the nuances are significant. Rather than being simply the trigger in each instance of violent behaviour, HIV can be a weapon of control wielded on a long-term basis. It is also central to a man's decision to remain with or leave a violent partner, an outcome often determined by the specific HIV status of the victim and/or his violent partner [3].

However, while GBV is not exclusive to women, many studies indicate a higher incidence than any other group – and women who have experienced violence are up to three times more likely to be infected with HIV than those who have not [4]. Violence against women diagnosed with HIV can be present, or manifest, in many ways, which can

be overt or covert. It has been defined as: 'any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm' [5].

## Links and outcomes

It has been established that GBV manifests, or has associations, within the areas of: HIV transmission, childhood abuse and disclosure – which must be kept in mind and further researched if we are to succeed in limiting any of these problems.

The issues were summarised as far back as 1999 by the then UNAIDS Executive Director, Peter Piot:

'Women often cannot insist on fidelity, demand condom use, or refuse sex to their partner, even when they suspect or know he is already infected himself. And they often lack the economic power to remove themselves from relationships that carry major risks of HIV infection. ... Women, fearful of getting beaten or thrown out, are unlikely to ask their boyfriends to wear a condom, or question them about fidelity.' [6]

### *Transmission*

GBV and gender inequality are important determinants of HIV in women, with GBV often a factor in HIV transmission, especially where there are controlling or violent male partners. Such men are more likely to have other sexual partners as well as their regular partner, with a resulting higher likelihood of transmission. Also, this setting carries the potential for forced sex resulting in injury, which increases the risk of HIV – a risk increased further by a refusal to use condoms.

This association is increasingly recognised globally, although wider research is needed [7]. Studies to date have been conducted primarily in the United States – or in sub-Saharan Africa, where GBV has been noted as key in the spread of HIV/AIDS infections. Thus those organisations working to counter the spread of HIV are increasingly prompted towards eliminating GBV as the best means of achieving this goal [8].

### *Childhood abuse*

Experiences of physical or sexual abuse as a child may also be relevant. Researchers have proposed a hypothesis for 'a continuum of risk' where abuse in



early childhood leads on to domestic violence later in life, commonly a risk-behaviour setting where transmission is more likely [9]. Specifically, data in this study demonstrated a strong correlation between childhood sexual abuse and:

- lifelong domestic violence;
- high-risk behaviours including drug use;
- having more than 10 male sexual partners;
- having male partners at risk of HIV infection;
- exchanging sex for drugs, money, or shelter.

### Disclosure

The Pan American Health Organization states that women who disclose may face abandonment by partners, families and friends, as well as violence because of their status [10]. If a woman holds back from informing a sexual partner of her HIV status, the result may be a transmission – followed by prosecution. Other potentially damaging outcomes are delay in accessing appropriate treatment, or the threat of disclosure to others in controlling situations – scenarios explored by a recent study of intimate partner violence presented at the British HIV Association's Annual Conference in 2012 [11].

*Intimate partner violence (IPV)* can be defined as: 'physical, sexual or psychological harm by a current or former partner or spouse' [12]. A study undertaken in an inner-city HIV clinic to explore the issue of IPV found that women's experiences of IPV fell into four main categories within the HARK questionnaire: Humiliated (45%); [feeling] Afraid (33%), Raped, (20%) and Kicked (33%) [13]. The Between the Sheets project, run in Liverpool during 2012, enabled women to explore the effects of living with HIV in relation to their sexual activity [14]. An initial evaluation demonstrated that 43% of attendees had experienced abuse or violence within a sexual relationship as a cause or consequence of HIV. Of relevance also is that women with HIV who live in areas of lower prevalence, such as Liverpool, are likely to experience greater isolation and marginalisation due to less available support services.

## Fighting back: current status

### Feasibility study

Recent research has set out to explore and highlight the HIV-GBV intersection. A feasibility study [15], launched [16] earlier this year, looked at the potential of a national investigation of GBV and HIV for women in the UK, posing the question, 'Do internationally recognised links between HIV and GBV have relevance in the UK?'

The executive summary noted that, in comparison to international research, the link between GBV and HIV in England is under-researched and relatively unacknowledged. Interviews with women living with HIV (WLHIV) demonstrated a broad range of

experiences. Certain complexities within migrant communities were highlighted, where financial and social dependence on the perpetrator is commonplace; and the concept of 'layers of stigma' was described, whereby HIV and GBV may lead to double stigma. A need to strengthen and maintain awareness and current knowledge among non-HIV professionals was emphasised: otherwise they may lack understanding of the social and biomedical complexities that HIV presents.

### Study conclusions

Additional useful input and suggestions emerged during discussions at the study launch event, held at the House of Lords and attended by a wide range of HIV experts and other interested parties [16]. These have been combined with the study conclusions, and the resulting recommendations for policymakers and service providers are as follows:

- Formal recognition by Government of the link between GBV and HIV;
- Better training for healthcare professionals in human rights and identifying GBV;
- Support for peer networks in empowering WLHIV to overcome GBV;
- Better human rights awareness for WLHIV;
- Improved mapping of HIV support services; plus development of partnerships with sectors already involved in aspects of this work;
- Production of a practice guidance toolkit, to recognise the many challenges faced by WLHIV;
- Development of training packages to challenge those cultural norms which accommodate GBV against WLHIV;
- Undertaking of long-term mixed-method research to a) determine the breadth of the HIV-GBV intersection and b) understand the impact of GBV at both individual and societal level.

### Policy recommendations

Two broad-based aims recently proposed within the outpatient IPV study mentioned above [11] are:

- Universal screening; ■ Greater IPV awareness.

### Coalface tactics

Practical considerations for those working in violence prevention and HIV care include awareness of the following [17]:

*Effects of stigma:* Social stigma, from either HIV or IPV or both, can cause negative stereotypes to be internalised and believed, which deters at-risk individuals from being frank about status, fears or conditions.

*Signs of overlap:* It is essential to know and notice signs of potential overlap between HIV and IPV.

*Care with disclosure:* Partner notification in an abusive relationship requires extreme caution.

The victim may not be ready to leave the relationship and appropriate planning is essential.

*Trauma histories:* PLHIV often have a history of trauma, so counselling and support plans should address and include this.

*Couples testing/counselling:* This strategy for testing was first added to the VCT priorities of PEPFAR in 2006 and has proved its worth in recent years [18]. It is developing well as an approach, demonstrating that male partners of pregnant women are supportive of their partners undertaking HIV tests, with a primary concern being the health of the baby. It is expected that HIV testing will be expanded to male partners in antenatal settings.

## Other initiatives

The GBV feasibility study showed that issues relating to HIV and GBV are gaining recognition. Other recent ventures in this area have included:

- Work in progress by the National Institute for Health and Care Excellence (NICE) to develop public health guidance on preventing and reducing domestic violence, expected in the public domain in 2014 [19];
- The addition of the UK's signature in June 2012 to the Council of Europe's Convention on preventing and combating violence against women and domestic violence [20];
- Recent focus on GBV and HIV in the African Health Policy Network's (AHPN) autumn 2012 conference (organised by its Ffena group) [21].

## Conclusion

In times of austerity such as now, we face unprecedented funding cuts that will limit much-needed projects and research in areas such as this. Therefore, those of us privileged to receive such sensitive information from women living with HIV should respond to the best of our ability – proactively sharing interventions and outcomes with our peers to offer the best response possible in the current climate. Perhaps we also need to establish ways of storing this valuable data in a national information base, where all areas of the country can be represented.

The message imparted at the event, was: 'Seize the moment' ... the moment to raise awareness about GBV and HIV, to start influencing others to recognise this link – whether overt or covert – and to support women and halt its progress.

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# 'What are you trying to say?'

## Communication training for HIV nurses: study day outcomes

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### Background

Patient concerns are all too rarely expressed by patients or identified by healthcare professionals, and they cause long-term distress when not addressed. Whether physical, psychosocial or spiritual concerns, many patients are reluctant to raise them due to commonly held expectations and assumptions. These include the belief that raising them is up to the healthcare workers – who are often seen as too busy or important to be burdened with patient concerns. Also, patients may lack the confidence, social skills or vocabulary to ask questions, or may be too embarrassed to raise certain difficulties [1–3].

Similarly, healthcare staff are generally poor at detecting even severe levels of distress in their patients and fail to enquire about patient concerns – or may even block patients' attempts to communicate them. Ultimately, these communication failures mean patients' concerns go unattended, which in turn increases their anxiety and stress [4–6].

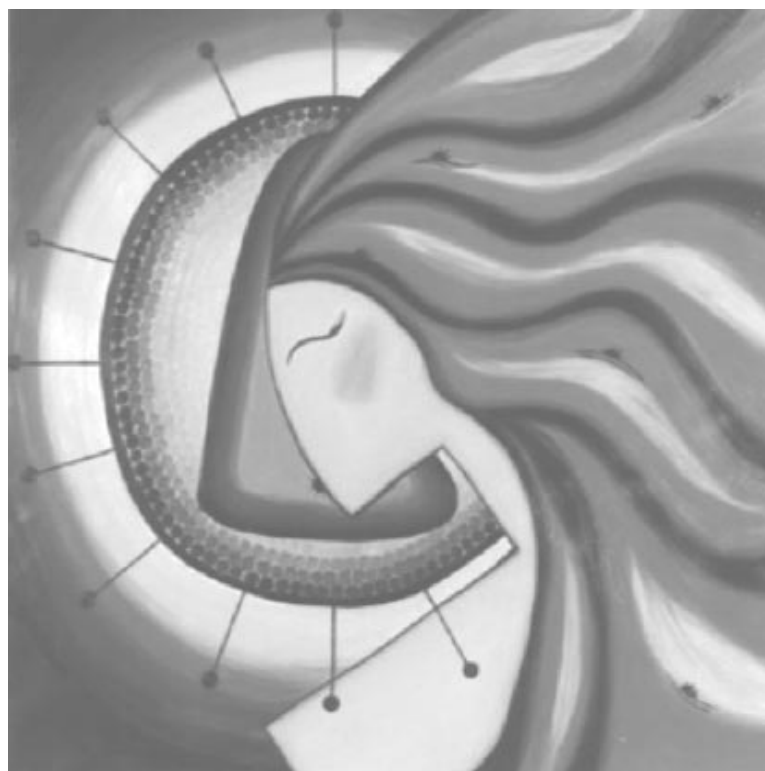
Lord Darzi [7] reported that patients in all settings give high priority to communication as a key aspect of care, wanting above all to be treated with humanity, dignity and respect. A lack of patient focus costs the NHS a great deal of time and resources. Improving communication is therefore not only about giving patients what they want and value, it is also about optimising the use of public resources.

Poor communication impacts on psychological distress and morbidity, treatment adherence, quality of life, satisfaction with care, complaints and litigation – and, finally, stress levels in healthcare professionals.

Research tells us that the consequences of poor communication are many and varied, significant among them being the impact on psychological morbidity. It is important to focus on how we might help patients voice their concerns, given that research over the past decade has suggested that:

- patients do not disclose many of their concerns;
- healthcare professionals do not always respond adequately to those issues that are disclosed [8].

Communication skills training is designed to give healthcare professionals the skills and confidence needed to elicit patients' concerns. Although the consensus is that such training is an important



Course artwork: *Contagious beauty* – artist: Hunter Cole. More information: [www.huntercole.org/artgallery/abstractionsonbiotechnology/hivpainting.html](http://www.huntercole.org/artgallery/abstractionsonbiotechnology/hivpainting.html)

aspect of care, its desired content and approach is still the subject of some debate [9].

### Study day development

The *Standards for psychological support for adults living with HIV* [10] state, 'Good communication skills underpin all elements of care ... those who must communicate particularly complex or distressing information should have enhanced communication skills'. With this in mind, a study day was developed (Panel 1) in partnership with the Maguire Communication Skills Training Unit. This specialist team of communication skills trainers has a 30-year history of research and training in patients' psychological adjustment to illness and their support needs; as well as key communication skills and how to teach them.

The study day's design observed quality benchmarks proven effective in other disease areas. The course content centered on participants' responses to the personally identified learning needs of their fellow participants, underpinned by current evidence on effective communication skills. Interactive teaching methods were used to



demonstrate key communication skills in action, and an opportunity was provided to practise key skills and receive feedback in a safe learning environment.

#### Panel 1: project aims

- To develop a study day addressing the communication challenges that HIV nurses face within clinical practice;
- For participants to look at developing/identifying a skills set that compliments existing skills;
- To organise participants' existing communication skills so as to facilitate patients' disclosure of concerns;
- To assess the impact on participants' self-efficacy and outcome expectation scores following completion of the study day.

## Course procedure

Participants were asked to attend a one-day cue-based communication course designed to support HIV nurses with the challenges they face in clinical practice. This course will act as a pilot study, to help guide and shape future courses of this nature.

### Pre course

Prior to attending, participants were asked to complete:

- i) a *pre-course workbook* (completion time, about 30 minutes), looking at communication issues and the evidence base around communication skills. They were also asked to consider issues from their own clinical practice.
- ii) *self-efficacy and outcome expectation questionnaires* to explore current skills and record outcome expectation.

### Post course

After completion, participants received:

- i) a *post-course workbook* to help consolidate skills and knowledge learnt on the study day. Standard consultation structures were included for:
  - initial assessment;
  - breaking bad news;
  - dealing with anger;
  - dealing with distress.
 Also included was guidance on:
  - challenging misconceptions;
  - non-adherence;
  - risk-taking.
- ii) a *journal article pack* to support their learning through further reading.
- iii) *self-efficacy and outcome expectation questionnaires* to be repeated for assessment purposes.

## Assessment approach

- i) *self-efficacy*: Pilot study participants ( $n=20$ ) were asked to subjectively rate self-efficacy for 16 skills or situations using a modified version of the self-efficacy questionnaire format developed by Parle *et al.* [11], based on Bandura's assessment method [12], which is a standard measuring questionnaire used in communication skills training [13]. Each response offered a range from 0 (not confident) to 100 (totally confident).
- ii) *outcome*: Participants' views on the likely consequences of their communication behaviour were assessed subjectively using a modified version of the validated outcome expectation questionnaires [11–13]. This was developed following an extensive literature review of the factors that affect healthcare professionals when assessing patients' concerns [9]. Each of the 19 questions are rated using a five-point Likert scale from 1 (very likely) to 5 (very unlikely).
- iii) *feedback*: Participant feedback was sought on:
  - course content;
  - supportive material;
  - perceived transferability of skills to practice;
  - recommending the course to a colleague.
- iv) *dialogue*: Participants were also invited to provide feedback to the researcher at any subsequent point, by sharing their personal reflections.

Both sets of questionnaires were completed pre and post workshop and analysed for changes.

## Study results

- i) *self-efficacy*: A rise in self-efficacy scores reinforced anecdotal evidence that participants felt they knew how to get to a patient's feelings, but were unsure how to manage these once elicited. Markedly increased scores were noted in:
  - perceived ability to explore feelings with patients in depth;
  - confidence in disclosure of concerns.

Participants became more positive about the benefits of helpful communication behaviours, feeling they would take the following skills back to clinical practice:

- (a) enhanced cooperation with patients;
  - (b) verbal/non-verbal cues;
  - (c) sharper focus on patient concerns;
  - (d) greater use of silence in consultations – time for patients to process information and formulate questions.
- ii) *outcome expectation*: Results showed consistent improvements, which mirrored what

is observed within the wider literature. Expected changes in attitude included:

- less assumption that patients would raise important concerns without prompting;
  - reduced sense of responsibility for solving all patient concerns;
  - increased confidence in ability to respond to difficult questions.
- iii) *feedback*: All 20 participants said they would recommend the course to a colleague. The course content and supportive materials were felt to be of a high standard, informative and transferable to the practice setting. Despite the researcher's initial reservations, the vast majority would have liked more interactive sessions.
- iv) *dialogue*: Content evaluated immediately after completion was repeated via email 1 week later, to allow opportunity for reflection, including suggestions for future study days. Considered responses following this interval included that participants would henceforth:
- use empathy more;
  - avoid giving information too soon;
  - resist the urge to correct patient errors in medical terminology.

## Discussion

Until recently, psychological distress remained the elephant in the room. The psychological standards aimed to address this by calling for services to meet these demands – hence the increased urgency for communication skills training. The standards advocate the need for this training, proposing a tiered system of psychological support in which nurses play a central role.

The use of a cue-based assessment and interviewing approach has been shown to enhance patient outcomes, satisfaction and treatment compliance – while reducing consultation times and complaints. Participants on the pilot study day report having had the opportunity to test this approach in situations relevant to their role.

## Conclusion

We talk to patients more than we perform any other clinical activity and should not make any assumptions in this area. Communication skills do not necessarily improve with time and experience – experience may simply be an excellent reinforcement of bad habits!

## Acknowledgements

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# Case study: an MDT approach to complex medical, psychological and social needs

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## Background and introduction

The multidisciplinary team (MDT) model of care has developed to meet the complex medical, psychological and social needs of people living with HIV [1].

A multidisciplinary team approach can benefit both patients and health professionals. Advanced nursing skills can be applied within the MDT to provide person-centred, evidence-based nursing care and interventions. Multidisciplinary collaboration can promote a comprehensive, holistic view of patients' needs through the availability of a range of skills and access to mutual support and education [2]. We have found that working with people with different professional backgrounds and different priorities can be challenging, and certain aims and principles are central to a positive outcome.

## Required skills and approach

Lack of communication between different professional groups is a common pitfall in collaborative practice, reducing consistency and continuity of care [3].

It is important to understand and appreciate what other members of the MDT contribute. The patient's outcome is maximised where there is reciprocal respect and effective communication among team members – who give up control in some areas, trusting the ability of others to provide appropriate care. We have achieved this by taking the lead in coordinating patients' care using good communication and management skills. Necessary components are summarised in Panel 1.

### Panel 1: Facilitators for effective MDT working [2,3]

- Good communication between professionals
- Committed staff
- Good leadership/management
- Understanding and appreciating the roles and contributions of other professionals
- Mutual trust and respect between professionals/agencies
- Networking
- Sharing information/knowledge through collaborative practice
- Appropriate staffing/workload levels

## Study aim and outcome

The aim of this case study was to explore the impact of a multidisciplinary team on the quality and outcome of care for HIV-positive people. The results demonstrate that delivery of effective care required collaborative working between all the parties listed below:

- hospital HIV clinical nurse specialists (CNS)
- community HIV clinical nurse specialists
- voluntary organisations
- Armistead (a sex-worker support organisation hosted within a community NHS trust)
- social workers
- drug and alcohol teams
- police
- prison service
- GP practice
- pharmacists

## Discussion and review

### *Responding to research*

Effective care for patients such as Sonya (see Case study, opposite) is associated with a range of routine goals and proven tactics (Panel 2), set alongside the key facilitators outlined in Panel 1.

### *Guiding principles*

Research in this area has helped formulate our MDT response, as follows:

- *Too much, too little, or contradictory information is associated with higher levels of anxiety and depression* [4]. Good management and leadership, along with effective communication, ensured that all MDT members were working towards the same goals and gave the patient similar information (Panel 2).
- *Effective communication by health professionals can help patients to convey any physical or emotional needs they might have* [5]. This patient responded well when we communicated at an emotional level by showing empathy and warmth. We gained her trust so that she disclosed her worries and concerns; and we established the need for antidepressants which the hospital doctor prescribed early in her prison sentence. As nurses who have a therapeutic

*Continued on page 12*

## Case study: Sonya (2008–present)

*The patient is a 28-year-old female sex worker with highly complex medical, psychological and social needs – called 'Sonya' for the purposes of this study.*

Sonya was diagnosed HIV positive in 2008 by her GP practice, which runs drop-in sessions for sex workers and other vulnerable adults. These sessions operate with outreach support from one of our hospital-based nurse practitioners, collaborating with both the surgery and Armistead.

Sonya initially accessed regular HIV review at the Liverpool Royal Hospital with input from her GP, our outreach worker, the hospital CNS and Armistead. She then presented to the Liverpool Centre for Sexual Health with general lymphadenopathy and splenomegaly. However, her CD4 count was 421 and she did not require antiretroviral therapy (ART).

Sonya was a sex worker and had a longstanding problem with drink and drugs. Her partner was serving a prison sentence for assaulting her. At the time of diagnosis she was stable on methadone but it was thought that she may have been taking street drugs as well. However, she was still drinking excessive amounts of alcohol. Her two children lived with relatives.

She was very reluctant to have her children tested. Struggling with her own HIV diagnosis, she felt she would be unable to cope if the children tested positive. However, from the health professionals' point of view, and in line with the consensus document *Don't Forget the Children*, this was a matter of clinical urgency [6].

Therefore the hospital CNS, paediatric CNS from Alder Hey Children's Hospital, and a support worker from Armistead worked closely together with Sonya and her relatives and finally gained permission to test the children: they were negative.

Her social circumstances changed in 2009. She was living with her abusive partner again after his release from prison. Still a sex worker, she continued to drink excessive amounts of alcohol and started taking heroin and crack cocaine again. This chaotic

lifestyle marginalised her from the rest of society and put her at higher risk of developing depression and other mental health problems. At this stage, the hospital CNS team were unable give psychological support through the stepped care model recommended in the 2011 standards [4]. This was because, despite the clear pathways in place, Sonya declined referral to mental health specialists such as psychologists, psychiatrists and counsellors.

It has been reported that good communication can develop trust and encourage disclosure of problems that might otherwise not be revealed [5]. The use of empathic communication allowed Sonya to disclose feeling low in mood, although she declined any intervention including GP referral for antidepressants if appropriate. Despite accessing a drug intervention criminal justice service (Addaction) for her drug problem, she continued to decline help from the community CNS team.

Although the police were aware of the abuse from her partner, Sonya chose not to prosecute and was assessed to have mental capacity from a safeguarding point of view. Despite continued efforts from the multidisciplinary team, she continued to decline any input, including psychiatric assessment or help from a psychologist or counsellor.

A multidisciplinary team meeting was held in 2009 to discuss Sonya's complex problems. Present were her consultant, hospital CNS, nurse practitioner/outreach worker, support workers from Addaction, the GP, and the vulnerable adult lead, who used the MeRIT process (Merseyside Risk Identification Toolkit) to assess her current status. The resulting high score passed the MARAC threshold (Multi-Agency Risk Assessment Conference) – the point where co-operation by all agencies involved, through voluntary meetings, is generally seen as a required component of care [7].

Shortly afterwards, she was admitted to the ID Unit at the Royal Liverpool Hospital with haematemesis, deranged liver function and rapid weight loss.

*Continued overleaf*

### Panel 2: Routine goals and effective tactics in MDT working

#### Routine MDT goals

Improve holistic care of patient  
Encourage healthy lifestyle  
Provide environment to build trust  
Monitor baseline bloods across HIV services  
Commence ART when needed  
Prevent onward transmission

#### Effective tactics (see also Panel 1)

Establishing a common goal between professions  
Good communication between practitioner and patient  
Personal commitment: leading by example  
Education: sharing good practice and knowledge with MDT colleagues through presentations at regular meetings  
Weekly multidisciplinary team meetings  
Fortnightly hospital CNS meetings



*Continued from overleaf*

Whilst in hospital, Sonya was supported through detox by the hospital CNS team, drug and alcohol specialist nurse and vulnerable adult lead.

Sonya was in a cycle of problems which included depression, demoralisation and substance abuse, leading to cognitive impairment and impulsivity and complicated by her HIV infection. Addiction and her GP were working closely with her during this time. She was continuing as a sex worker, which raised concerns regarding onward transmission, even though she stated that she was aware of the legalities around HIV transmission and always used condoms.

Sonya began to miss hospital appointments, despite support from the hospital and community CNS teams. The community CNS team monitored her baseline bloods and encouraged hospital clinic attendance. She then became severely immunocompromised, with advanced HIV infection. A support worker from Armistead encouraged her to access treatment and, with support from the hospital CNS team, she commenced ART.

During this time, Sonya was convicted of assault and commenced a prison sentence. The hospital doctors and hospital CNS collaborated closely with the prison medical, nursing and administration staff. She was commenced on antidepressants to alleviate low mood, attended regular hospital clinic appointments and continued on ART.

Sonya was empowered to take her ART by the hospital clinical nurse specialists, who worked collaboratively with prison nurses and provided leadership and a consultancy function as required. We also had a supportive role in helping her manage living with HIV. We arranged necessary blood tests and investigations in collaboration with the prison services and provided the treatment and care needed during her prison sentence. Together

with Sonya, we made a plan for her ongoing nursing care, with an emphasis on health education and preventative measures.

In August 2010 her CD4 count had risen to 442 while viral load had dropped to 106. By January 2011 her CD4 count was 522 and viral load was undetectable. Her adherence was excellent. She was alcohol and drug free.

However, on release from prison, Sonya began to drink excessively and take drugs again. She breached her probation and was sent back to prison. Following release from prison a second time, she was referred to a community-based alcohol and drug support service but did not attend. The community CNS, in collaboration with the hospital CNS team, continued to liaise with her and with alcohol and drug support.

In 2012 she became non-adherent to her ART. Despite motivational interviewing techniques, brief interventions including referrals to various alcohol and drug services from diagnosis onwards, Sonya still had a chaotic lifestyle revolving around alcohol, drugs and sex work.

However she continued to take her ART. Both hospital and community CNS teams continued to collaborate, monitoring her routine blood tests and encouraging attendance at outpatient clinics for HIV care. Involvement continued from the probation service and the vulnerable adult lead for the hospital, and Sonya also received support from social workers and counsellors at Sahir House, a charity which supports people living with HIV and their families. Her mother has been very supportive throughout, which has been helpful for all those involved.

**April 2013:** having been awarded funding for 3 months' inpatient rehabilitation, Sonya is currently in a detox unit prior to this admission. This is a positive outcome – and timely, as she was about to be recalled to prison.

*Continued from page 10*

relationship with patients, both hospital and community CNS teams are in an ideal position to identify any psychological problems. We used the step care model from the 2011 psychological standards to decide what levels of care were needed by the patient in this study.

- *Patients who participate in decisions about their treatment plan have lower depression rates* [8]. We used informative communication to encourage the patient to take more interest in her condition so that she could develop a greater understanding and be involved in treatment decisions. She was also given the responsibility to take her own ART during her time in prison.

## Outcomes

The patient in this case study did seem to make the most progress whilst she was in prison, probably due to an imposed lifestyle change. However, during this time support continued from the hospital CNS team, as first point of contact for any problems during outpatient clinic appointments.

One of the most valuable outcomes was that Sonya did get an HIV test. This indicates that she was prepared to take some responsibility for her own health and wellbeing.

Through the perseverance of the multidisciplinary team, she is now accessing HIV services on a regular basis. Considering her history, this is a major

achievement – allowing ongoing engagement and monitoring, for the best possible outcome. She was also sufficiently engaged to give consent for testing of her children, who were thus established as HIV negative.

On occasions we have been short staffed, with a large cohort of patients to manage. However, through good working relationships between the hospital CNS team, the community CNS team and other agencies, we feel we have succeeded in providing a seamless service, with consistency and continuity of care.

## Conclusion

Multidisciplinary team work is essential in order to meet the holistic needs of our HIV-positive patients.

We have had varied success. Progress is slow with some individuals. However, every step forward is valuable.

Above all else, members of the multidisciplinary team need to communicate effectively with each other, and the patient and their family, to provide the best outcomes for the patient.

Based on experience and dialogue, we have put a framework in place to make multidisciplinary working as effective as possible, employing the various routines and strategies described above. However, it is important to remember that there is always room for improvement.

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#### Issue 13.2 (August)

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#### Issue 13.3 (December)

Copy deadline: Friday 28 October 2013

# Evaluating culturally appropriate counselling for childbearing migrant African women

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## Research project title:

The meaning and experience of receiving HIV post-test psychological counselling, using an innovative culturally appropriate model in comparison to classical western models, for childbearing migrant African women in the UK: an interpretive phenomenological analysis (IPA).

## Introduction

The third decade of the HIV pandemic is an era in which highly active antiretroviral therapy (HAART) has transformed HIV into a chronic manageable illness [1]. Nonetheless, most people living with HIV (PLHIV) experience both the psychological impact of living with the virus and that of coming to terms with the diagnosis [1,2], as they access counselling at different transitional stages. Much noted is the greater incidence of major depressive disorders and anxiety compared with HIV-negative counterparts [3].

## Context

Giving PLHIV an opportunity to talk through their fears and concerns using talking therapies contributes to mental wellbeing and physical health [4]. Although African PLHIV represent the UK's second largest group affected by HIV, after gay men [5], they are reported not to engage well with counselling and psychotherapeutic services. Very little is known about the reasons for their reluctance to access such services, although a 2001 service-user feedback survey by Terrence Higgins Trust (THT) shed light on some of the reasons. Misunderstandings and misinterpretation of their emotional responses meant the Africans affected [6, 7] were three times less likely to be referred to specialist mental health services than their non-African HIV-positive counterparts – with referrals mostly at advanced HIV stage in a context of organic brain disease or major depression [8].

Thus a gap in the service provision was demonstrated [6, 8–9], as HIV-infected Africans continued to present late for diagnosis, many with comorbid severe mental health needs [10], often compounded by isolation, stigma and the complexities of integration and settlement [11–13]. THT responded by developing an African Emotional Support (AES) counselling model, and in 2003 reported a counselling uptake of 47% –

compared to 7% in 2001, prior to using AES – with subsequent uptake continuing to rise. Therefore, 'within the context of HIV, the problem is not African cultures, but the misunderstanding and misinterpretation of cultures' [7].

## The AES service

THT's African Emotional Support counselling model is a culturally appropriate service delivered by qualified African counsellors, psychotherapists and counselling psychologists [14]. It seeks to provide an alternative to the traditional classical western counselling (CWC) approach, by working responsively and appropriately with African/Afro-Caribbean communities, where sociocultural complexities often compound the stress of living with HIV [2,6,8]. This model supports the historic tenet that psychological counselling for PLHIV must work within their sociopolitical context [15]. Additionally, it had been observed that certain cultural issues (eg, specific beliefs, and issues around HIV-positive childbearing women) may require specific approaches in post-test counselling [16]. More recently, NICE guidance has emphasised the need to consider ethnic and cultural backgrounds [4], and cultural background has also been noted as a significant factor in psychological wellbeing following HIV diagnosis [10].

There is, however, very limited information about the meaning, experience and impact in counselling psychology and psychotherapeutic practice of culturally sensitive models – and of assumptions made when providing the CWC model as a 'one size fits all' approach.

This AES team is now an experienced provider and advocate of a culturally appropriate service which was recognised in 2004 with an award from the British Association of Counselling and Psychotherapy, for innovative client care practice and advancement in psychotherapy practice. There is anecdotal evidence that the approach is effective; however, there are no standardised, research-based, post-test counselling protocols.

## The research

Childbearing African migrant women represent a large group infected with HIV, often diagnosed through routine antenatal testing and accessing services more than other groups [17–20]. Thus their

experiences and perceptions are crucial in planning and delivering services that are fit for purpose. Therefore, my research is a review of the innovative, culturally sensitive HIV counselling service provision to these users – given the recommendation of the need for such a service [17–21].

#### The main research question was:

What is the meaning, experience and impact of AES provision to the HIV-positive migrant African woman service-user?

To establish whether, and to what extent, the AES counselling model is suitable for HIV-positive clients, I broke the question down, as follows:

- i) What assumptions are we making when we provide a CWC model to UK African migrants? How do participants experience receiving AES counselling only?
- ii) How do participants compare experiences of the two forms of counselling (CWC then AES)?
- iii) How can HIV counselling be improved for the most represented service users, the HIV-positive African migrant women?
- iv) To what extent does an existential philosophical framework accommodate the philosophical stance on 'self' of the migrant African HIV-positive client?

## Objectives

- Gain an in-depth understanding through exploration of the lived experiences of 15 HIV-positive African childbearing migrant women living in London, UK;
- Compare and explore the experience of receiving two different counselling service models (CWC then AES) – Arm 1; with experiencing only AES – Arm 2;
- Investigate and evaluate differences in efficacy between AES and other counselling models; and inform policy.

## Literature review

A systematic critical and historical literature review was conducted. A search was carried out for relevant sources likely to produce the strongest evidence for the research question and topic, taking into account hierarchies of evidence [22,23] and assessing new perspectives with critical examination of research methods used [23]. Relevant journal articles, books and grey literature were accessed, using the keywords: Africans with HIV, Africans with HIV/AIDS, women, HIV counselling, culture and migration, counselling, refugees, culturally sensitive counselling, and migrants/immigrants. The inclusion criteria targeted the following areas:

- global and national outlook for HIV;
- impact of shock, denial, stigma, prejudice, identity;
- cultural immigration issues and broader circumstances of HIV-positive black Africans in the UK;
- existential work on HIV diagnosis (death, guilt, freedom, spirituality, mental health needs; existential anxiety, loneliness and depression);
- associated health inequalities;
- culture and counselling (distilled down to: i)HIV counselling and ii)the notion of culturally sensitive counselling.

## Culturally specific versus existential counselling

The World Health Organization (WHO) declared in 1978 the need for culturally sensitive support for people suffering from psychological disorders and stress [21]. Twenty-six years later, very few countries had taken any action in response to this call [24]. Nonetheless, there is a plethora of literature dating back over three decades on varied aspects of culturally appropriate counselling in mental health, looking at the provision of culturally sensitive, cross-cultural, intercultural and multicultural counselling.

However, there is scant literature on this notion in the context of HIV counselling. It can still be argued that, 'the uncritical application of western models, ... applied without rigorous attention to the longstanding critiques concerning the necessity for cultural appropriateness and concern for contextual factors, therefore generally has questionable efficacy and renders them at best ethnocentric' (and at worst tantamount to 'oppressive') [25].

For culturally specific counselling to be effective, counsellors must understand individuals' cultural backgrounds, behaviour and world views to avoid misconceptions about the causes of their behaviours [26,27], a requirement that is often overlooked in counselling and psychotherapy [28].

In existential counselling it is of fundamental significance to understand a client within the four dimensions of human existence – *Umwelt*, *Mitwelt*, *Eigenwelt* and *Überwelt* (Panel 1). Both the client's and the therapist's philosophy is relevant to the *Mitwelt*, their relationship with the world, the social/public dimension where we relate to/interact with others. This also applies to culturally specific counselling.

## African concept of self

Exporting counselling from western to African cultures is problematic because the theoretical assumptions that underlie it derive from a western cultural assumption of 'self' [31,32]. African cultures



**Panel 1: Existential therapy – Ludwig Binswanger, 1881–1966 [29,30]**

Binswanger was a Swiss-born psychiatrist who is known for his pioneering work in existential psychology. He was particularly interested in phenomenology and existential philosophy, and attempted to bring some of these elements into his therapy. Existential thinking seeks to avoid categorising or labelling people but instead focuses on the levels of existence which people encounter:

Umwelt	the physical, biological dimension, one's embodied existence
Mitwelt	the 'with world', the interpersonal world, the social/public dimension, the territory of social interaction
Eigenwelt	the personal/psychological dimension comprising one's sense of identity
Überwelt	the spiritual dimension referring to one's ideology and philosophical outlook

emphasise the interconnectedness between people, the natural world and the self in interrelationships with others [31]. This interconnected viewpoint has been described as follows: 'when an individual suffers or rejoices, she does not do so alone but within the cooperate group, when she rejoices, she does not rejoice alone but with her kinsmen, her neighbours, and her relatives, whether dead or living' [33]. It can be summed up by the adage: 'I am because we are, and because we are, therefore I am' [34]. In western counselling the psychological model focuses on the individual, whereas the African psychological model focuses on both the individual and their community [31].

### HIV, Africans, existential issues: gaps in UK literature

Existing work on Africans and HIV in the UK comprises mostly quantitative studies and has focused on:

- health promotion and service use (Padare Project) [35];
- behaviour modification, demographics, sexual attitudes and treatment needs (Maisha Project, SHIBA Project) [36,37];
- lived experience [17–20];
- access to life-improving measures [38];
- diagnosis, stigma and identity [10].

PLHIV suffer from existential anxiety, loneliness and isolation, helplessness and guilt [39,40]. Unfortunately, there is no process-based research data that inform us about the post-test counselling service-user experience of HIV-positive black African migrant women, hence the need to establish which HIV counselling approach is appropriate and effective for this service-user group: this was the ultimate aim of my study. More broadly speaking, work is also needed to explore the

efficacy of psychosocial interventions and the role of psychological support in the HAART era [41].

### Inclusion criteria

The aim was to achieve as homogenous a sample as possible, while observing the following requirements for each participant:

- African heterosexual refugee woman living with HIV (WLHIV), with settled immigration status in the UK for 2–5 years;
- Within the childbearing age range of 25–35;
- Low risk: no psychiatric referral or noted psychiatric disorders;
- Able to understand terms of participation and conduct research in English;
- Have received either both CWC and AES models, or just AES;
- Have received counselling under the London Councils funding project\*;
- Clients of other AES counsellors but not the researcher.

\* funds earmarked by certain local councils in London, for work that involves refugees and asylum seekers.

### Design and methods

Following New School of Psychotherapy and Counselling and Middlesex University ethics approval, plus site-specific risk assessment, participants were identified through THT's Counselling Service as those who had agreed during the counselling assessment interview to be contacted for research purposes. However, there was no obligation upon them subsequently, to participate once approached. A purposive sampling (where participants are selected because of certain known characteristics that lend themselves to the purpose of the study) of 16 African migrant women participated in in-depth, qualitative, semi-structured, recorded interviews lasting 45–60 minutes, conducted at THT's counselling suites. The aim was to recruit between five and eight in each arm, and eight per arm ultimately participated. Three of the five interviewed from Arm 1 were used for the research project pilot study report. This was assessed and passed, with comments received being used to inform the final modified interview guide for the main research study. For the main research, 15 (of the 16) participant interviews were used.

### Interpretive phenomenological analysis (IPA)

#### *Rationale for use*

Having considered the five phenomenological psychology research methods available (descriptive phenomenology; hermeneutic phenomenology; template analysis; critical narrative analysis; and IPA) [42], and based on the

research questions, a qualitative approach using IPA was judged the most appropriate to develop understanding of the holistic context of HIV diagnosis post-test counselling through the 'voices of experience', as the subjects describe their lived experiences and how they view reality [42,43]. Furthermore, IPA was indicated for this project because of several specific properties (Panel 2).

Fourteen participants had children, while one was a primigravida diagnosed before pregnancy. Three had been diagnosed during pregnancy, eight diagnosed through ill-health and five had contracted HIV through genocide rape and experienced gender-based violence. Of these, three were in serodiscordant relationships and had been diagnosed before marriage. Fourteen had at least a first degree, of whom ten were in employment. Two mentioned having contracted HIV in marriage with their first sexual partner. Ten received time-limited standard short-term counselling (12 sessions), while six had long-term counselling. Further sessions of long-term counselling (rather than short-term work) are offered on the basis of therapeutic need, for clients suffering from trauma (eg, post-traumatic stress disorder, rape trauma syndrome, victims of genocide and those with complex childhood issues).

## Preliminary data analysis

IPA was used for data analysis, and a six-stage recursive thematic data analysis method was undertaken for the verbatim transcription [54].

Participants explored their experiences and the barriers to effective helping, comparing the CWC model to the AES model. The following themes emerged:

### Panel 2: IPA – key properties

- Small sample size per arm [42];
- Recommended for psychological research [44], sexual health studies [45] and studies that explore 'feeling understood' and concern anger issues [46];
- Sensitive to content and committed to academic rigour: therefore a detailed personal reflective account was provided [47] providing transparency and coherence [48];
- Uses a two-stage interpretive process [49]: 'as the participants try to make sense of their world, the researcher is also trying to make sense of the participants trying to make sense of their world' [44]. This helps the researcher to obtain a detailed examination of the participant's life world, and a richer analysis is available because of the empathising component in questioning, interpretation and understanding [44]. This is significant and useful in this context, given the psychological impact of HIV diagnosis on individuals;
- Proven for use in HIV research [50,51];
- Also used in research involving experiences of psychotherapy [52]; and dealing with life transitions, identity and the impact of immigration on identity [53].

- initial apprehensiveness about confidentiality;
- existential issues associated with the impact of HIV diagnosis;
- the notion of therapist/client sameness;
 

*(This was viewed positively as it enhanced exploration of cultural issues and issues related to African communities, of helpful or not-so-helpful cultural beliefs, rituals, practices and religion.)*
- tensions, links and paradoxes between the African philosophical sense of interdependent self and the existential anxiety and implications of isolation/aloneness in the context of HIV diagnosis;
 

*(This was perceived as easier than with a non-African counsellor, which further helped in opening up. Participants expressed a general perception of not being understood when such issues were raised in CWC.)*
- counselling as a space to explore feelings and the impact of diagnosis;
- a need for long-term rather than time-limited counselling, expressed by some participants.

## Preliminary conclusions

Two key observations were made, both important for effective counselling. Firstly, participants emphasised the significant positive impact of situation-specific counselling by a counsellor from a similar cultural background rather than by a therapist of a different cultural background. Secondly, they stressed the role of their sense of African heritage and identity, which instils distinct values.

What also emerged were the implications of raising awareness in intercultural work and the associated psychological theories for training, as they apply to psychotherapeutic practice. Therefore, my recommendations relate to emphasis in training on such theories as 'othering' (the 'them and us' notion) and 'social identity' [55,56] – and the impact these have on psychotherapeutic work, enhancing intercultural professional competence when therapists work with those considered culturally different.

The completed research will be disseminated to inform policy guidelines and existential psychotherapy and counselling psychology, potentially including the Standards for psychological care [57], which are silent on the impact of culture on counselling. The research sheds light on the African communities I work with, through enhanced understanding of process and content in culturally sensitive counselling areas. Thus it is also hoped that the findings will benefit THT by establishing the efficacy, reliability and quality of its AES service.

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# From the ground up

Juliet Bennett

Independent Nurse Advisor

The 'functional cure' set off an avalanche of media coverage that sent mixed messages to the public. Immunology aside, we must stick to first principles and build with care, writes Juliet Bennett.

**M**ost people, when discussing a state of 'cure' for any disease, would consider this to be a situation whereby the causative infective agent and/or diseased cells have been entirely removed from the body – ie, an eradication cure.

## Keen for a cure

The notion of 'functional cure' has recently become a hot topic in the field of HIV. The term is intended to signify that we cannot currently prove with certainty that an individual with previous HIV infection has subsequently become HIV negative.

Factors which have fuelled recent renewed enthusiasm regarding the possibility of a cure include:

- an increasing understanding of the mechanisms of viral persistence;
- a growing array of therapeutic interventions with the potential to cure;
- targeted research funding directed at the search for a functional or an eradication cure.

### Functional, or eradication?

Only a handful of published cases have claimed 'functional cure', with the 'Berlin patient' [1] the most widely publicised case to date. However, none of these could claim to rule out all of the following circumstances:

- individuals were heter-

#### Panel 1: Resistance conferred by CCR5-Δ32 mutation

C-C chemokine receptor type 5, also known as CCR5, is a protein on the surface of white blood cells which acts as a receptor for chemokines. This is the process by which T cells are attracted to specific tissue and organ targets. Many variants of HIV initially use CCR5 to enter and infect host cells. A few individuals carry a mutation known as CCR5-Δ32 in the CCR5 gene, conferring resistance to these strains of HIV [2].

ozygous for the CCR5-Delta32 (Δ32) mutation (Panel 1) with strong HIV specific T-cell responses;

- minimal additional information was supplied;
- assays were of a lower sensitivity than comparable research.

The German patient received a bone-marrow transplant as a treatment for leukaemia. This transplant contained stem cells from a donor with copies of the CCR5-Δ32 mutation gene. After 20 months the patient's viral load was undetectable, both in the blood and in examined brain and rectal tissue. There had also been a successful reconstitution of CD4 T cells, including in the gut mucosa. Before the transplant, low levels of virus, which did not use the CCR5 receptor, had been detected in this patient but after the transplant, this type of HIV was not detected either. This was consistent with previous findings that cells expressing the CCR5-Δ32 variant confer resistance to a broad range of HIV variants. After 3 years, and to date, the patient has maintained the resistance to HIV.

### Hitting the headlines

In March this year, at the 20th Conference on Retroviruses and Opportunistic Infections (CROI) in Atlanta, a case study was presented on a baby born in Mississippi, USA [3].

The child was reported as being 'functionally cured of HIV' aged 23 months, and the media leapt on the news, publishing dramatic headlines including:

[4]

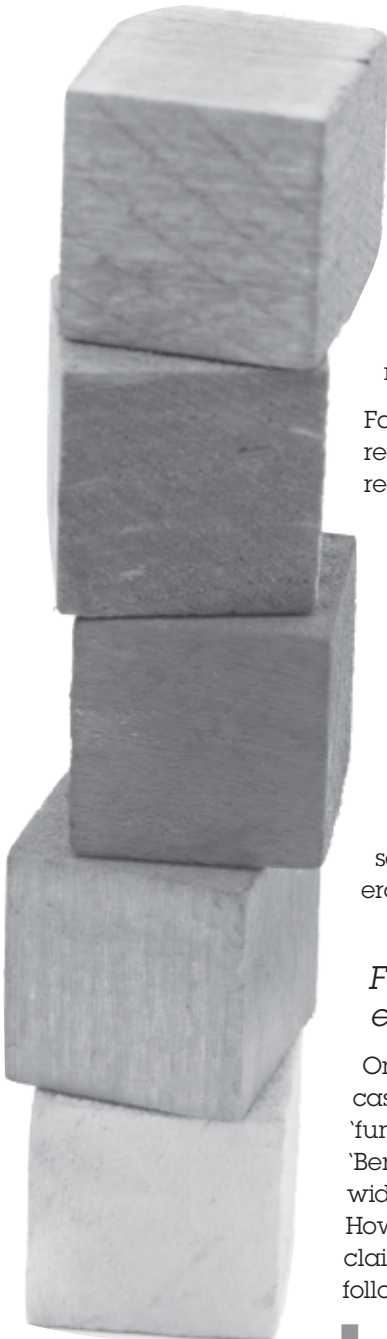
**First child cured of HIV**

[5]

**Scientists' hope for HIV cure**

**US doctors cure child born with HIV**

[6]



This led, understandably, to widespread excitement and inflated optimism. The National Institutes of Health's (NIH) 4 March press release, on the other hand, was a little more restrained, presenting readers more with a promising lead requiring further research:

'Toddler "functionally cured" of HIV infection. Discovery provides clues for potentially eliminating HIV infection in other children' [7].

Confusion ensued in the HIV community – although it has to be said that the conference presentation which triggered the media flurry was itself relatively cautious. The speaker had described the case as a 'proof of principle', meaning that a 'functional cure' of an infant may be possible – whilst also stressing that further research was needed.

### *A case in point*

In the excitement following what appeared to be a ground-breaking moment, some reports did not cover fully the unusual, perhaps unique, circumstances in this particular case:

- The child's mother received no prenatal care and was only diagnosed with HIV when she arrived at a rural Mississippi medical centre in premature labour.
- The delivery period was very short, so there was no opportunity to administer intravenous prophylaxis during delivery.
- The infant was tested and treated with HAART from 30 hours after birth for an 18-month period with a more potent triple therapy than is routinely administered in the US (AZT, 3TC and therapeutic doses of nevirapine, switching to Kaletra at day 7). Notably, this is standard of care in the UK [8].
- The child was lost to follow up at 18 months, for about 5 months.
- There is no evidence of an immune response against the virus. Genetic studies of both mother and infant showed no presence of the CCR5-Δ32 mutation or any HLA genes known to be associated with the control of viral replication.
- After she had remained off treatment for a further 10 months, following return to care, the John Hopkins Children's Centre reported that the child had maintained an undetectable viral load.

### *A continuing debate*

Sceptics have expressed a range of doubts, and debate continues as to whether this case represents a 'functional cure' or an example of successful post-exposure prophylaxis. It certainly raises several questions: did the early and highly potent regimen prevent the establishment of a durable latent reservoir of infected memory cells? (see Panel 2).

Furthermore, perhaps the infant would have cleared the virus even without treatment.

What has appeared in the past to demonstrate the same outcome has been otherwise discounted – for example, by sampling contamination/errors or insufficient data to justify formal conclusions [9]. Matters were further complicated in this particular case by a lack of stored blood samples which could have supported the evidence by allowing further investigation of the linkage between the virus in the mother and the infant. In addition, it is still rather early days and the child's viral load may yet rebound.

### *Prophylaxis, not cure?*

Some have argued the possibility that what has occurred here is really a transfer of virus from mother to baby – or that the infant may have been infected just a few days *before* birth, so recently that this was a 'transient' or 'acute' infection. This scenario implies successful aggressive prophylaxis rather than a 'cure'. However, given the infant's viral load of approximately 1.25 million copies at birth, the researchers presented this as evidence of a firmly established or chronic infection.

The use of language muddies the waters here, too ... we all know that HIV infection is on a continuum, from primary infection through to AIDS-defining illness. So where, on this continuum, does an attempt at prophylaxis become defined as an attempt at cure? There also remains contention over the definition of terms such as 'transient' or 'acute' infection, versus 'established' or 'chronic' infection.

### *Post-treatment controllers*

The findings of a French study just published have added to the debate. Fourteen patients with durable viral control were found at a number of French clinics and became the subjects of a study called VISCONTI (Virological and Immunological Studies in Controllers after Treatment Interruption) [10].

The researchers reported that these adults had started a course of HAART soon after infection, subsequently stopped it, and not had to re-start because they have, on the whole, maintained undetectable viral loads for at least 4 years (some for almost 10 years) after stopping therapy.

All cases reported had taken HAART for an average of 3 years before stopping, and started treatment within 10 weeks of infection, the majority starting at 4 weeks. The baseline viral loads were all relatively high (average 100,000 copies/ml). During their time off treatment, at the time of reporting, eight people had not had any detectable viral loads (ie, above 50 copies/ml) and only two people had had viral load above 400 copies/ml. CD4 counts at baseline averaged around 500 cells/mm<sup>3</sup>, increasing to an

average of around 900 when treatment was stopped, then either remaining stable or increasingly subsequently, in all study participants.

Interestingly, the study authors estimate that around 15% of people with HIV could subsequently become so-called 'post-treatment controllers' (PTC) if ART is started within 6 months of HIV infection and maintained for at least a year. However, this has clearly been hard to measure to date, since once having started HAART, few people stop treatment. This view is contradicted by many other studies [11,12] which have found no evidence that people who began treatment in primary infection could control HIV after stopping treatment; however, the French patients had taken longer-term treatment, compared to those in earlier studies who had only received treatment for 12 to 18 months.

## Emerging possibilities

### Reservoir cells

We know that HIV remains in cellular 'reservoirs' which contain its genetic code and provide a latent pool of virus in widespread sites including the brain, lymphoid tissue, bone marrow and genital tract. These reservoirs, or 'sanctuary sites' persist, even in the presence of HAART. Some mathematical models have shown that most people would have to be on HAART for 60–80 years before their HIV reservoirs were depleted [13].

There are considered to be a number of ways in which reservoirs of virus might persist:

- in sanctuary sites where drug penetration or potency is suboptimal;
- as integrated but 'silent' provirus maintained in long-lived cells;
- by low levels of ongoing replication that are incompletely suppressed by HAART [14].

Many researchers believe the best hope for true 'cure', or eradication, lies in using anti-latency drugs that will remove HIV from these viral reservoirs by forcing dormant, infected CD4 cells to become active, with HAART then 'mopping up' the released virus [15]. However, scientists still need a better understanding of the mechanisms that underlie viral latency and a fuller appreciation of the range of cells involved to be able to target latent HIV reservoirs effectively.

Trying to ascribe this scenario to the Mississippi baby, once again, raises some ambiguities:

- It cannot be established whether the child had a pool of latently infected cells before beginning ART;
- It cannot be proven whether she had any such pool at a subsequent point in time (although all available evidence to date indicates that there is no reservoir or virus with the potential to replicate in the child);

### Panel 2: T cell subsets

Several CD4+ T cell subsets have been identified in humans: naïve T cells which mount an immune response to a variety of new antigens, and memory T cells which respond to previously encountered pathogens. The memory T cell pool comprises distinct populations of central memory and effector memory T cells, characterised by distinct homing and effector functions. Variations in the number and efficacy of these are thought to account, at least partly, for the ability of some individuals to control HIV infection without using HAART [16].

- Recent research [17] has suggested that some virus may take a year to emerge from reservoirs (however, almost that period had elapsed before the CROI presentation, with no sign of viral emergence).

### Spontaneous controllers

In addition to the French cohort of post-treatment controllers (PTCs) described above, there is a group of rare individuals, called HIV controllers (HICs), who also maintain low viral loads. In contrast to those in the French study, these individuals are referred to as spontaneous HICs because they have never been on treatment. It appears that the amount of HIV DNA in some (*but not all*) of their memory cells, including the central memory cells (Panel 2) is close to that of other people with progressive HIV infection. Researchers have suggested that there is ongoing DNA activation in these patients but it is stopped by immune-system surveillance before actual viruses are produced [18].

### PTC versus HIC

Comparing the immune systems of PTCs and HICs, the mechanism for viral control is thought to have very different explanations. HICs tend to have antigens that respond only slowly to HIV infection (associated with slow disease progression), and a presence of cytotoxic T-lymphocytes that are particularly alert and efficient. In contrast, PTCs tend to have HLA types that are highly responsive to HIV (associated with fast disease progression), and to have experienced severe symptoms and very high viral loads during primary infection. PTCs have been shown to have a significantly lower proportion of HIV DNA in central memory cells, suggesting that the long-lived reservoir of potential new HIV replication had shrunk in response to HAART [19].

## The UK horizon

### Responding to patient reactions

UK nurses working in this field are inevitably approached by our patients expressing a range of emotions and viewpoints in light of such publicity. These can range from reserved curiosity, to great



optimism and excitement, or hard-boiled scepticism.

It is important to provide a measured, balanced and well-informed response. We must stress that the American baby was a single case, and that the French study is also based on small numbers of patients. These individuals were all diagnosed and treated very early with potent regimens that many with HIV do not start until some years after infection, even assuming no resource limitations. And crucially, for this small number of individuals, there is as yet no certainty that they will have permanent protection from disease progression. However, these findings could clearly be of interest on the rare occasions that mothers-to-be are diagnosed with HIV during labour, rather than pregnancy.

### Taking care of business

We all recognise the continued and significant economic and logistical obstacles that exist in making early HIV treatment accessible and widespread. In the UK, rolling out and normalising HIV testing, including continuing to screen all women presenting to antenatal care, will continue to be a priority. The key strategies and guiding principles by which we work can helpfully be communicated with patients, to varying degree depending on individual circumstances. The aim here would be to enhance patients' understanding of the issues involved and provide reassurance that HIV professionals are keeping essential tactics firmly in their sights (Panel 3).

## The global picture

### 'Breakthrough' versus reality

A first glance at the headlines could persuade many people not working in HIV that the Mississippi

#### Panel 3: Priorities for HIV professionals that have potential interest for patients

- Continue to maximise uptake of HIV testing for all at-risk populations including women in advance of, or early in pregnancy.
- Develop consensus for consistent advice (alongside effective methods of communicating this information), to women of childbearing age and families with HIV.
- Build robust systems for minimising instances where patients are lost to follow-up.
- Allocate resources for further research, including peer-reviewed evidence before publication, in cases such as this 'functional cure'.
- Consider strategies for predicting and managing media reporting of such findings, and the impact of such publicity on the HIV community.
- Seek consensus on the use of terminology such as 'functional cure', and clarify its significance for non-medical individuals.

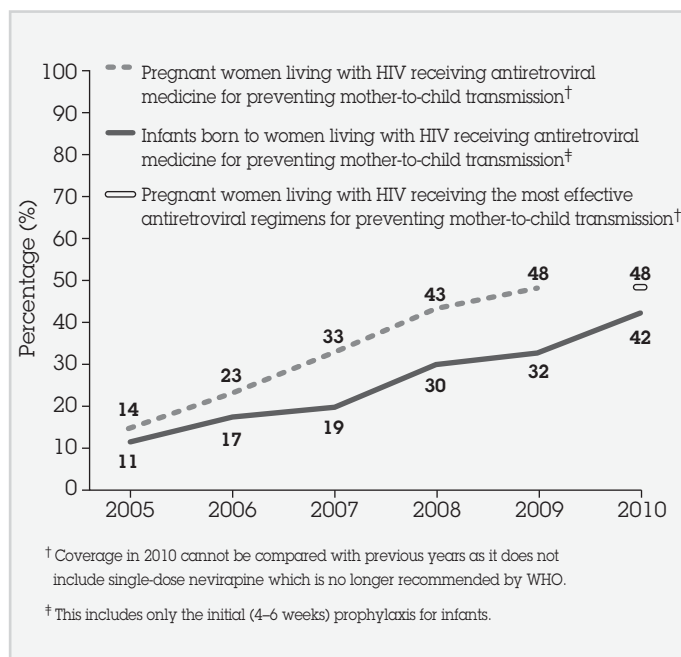


Figure 1: Treatment with antiretroviral therapy of pregnant mothers /newborns in low/middle-income countries 2005-2010 [adapted from 20].

baby breakthrough will save thousands of lives. However, we already know that treating in pregnancy can prevent infections in children. The real challenge is to ensure that the drugs and the medical staff are in the right place at the right time, to test and to treat at-risk individuals. For the foreseeable future it is clearly unrealistic, for example, to hope that the clinics pregnant women attend across sub-Saharan Africa will have access to the potent regimen, assays and care that the baby in this high-profile case received from skilled staff, within hours of her birth.

### Work to be done

Figure 1 summarises data recently reviewed by the World Health Organization as part of the drive towards universal access. It looks at treatment of both HIV-positive pregnant mothers and their babies, to prevent transmission; and at the extent to which optimum treatment is prescribed for these mothers.

Whilst progress is evident, these are average figures, which mask the huge disparities between and within countries. Unicef (the United Nations International Children's Emergency Fund) reports that countries such as Botswana, Lesotho, Namibia, South Africa and Swaziland already achieved coverage rates of more than 80% in prevention of perinatal mother-to-child transmission (PMTCT); while others, such as Eritrea, have only 3% of HIV-positive pregnant women enrolled in PMTCT programmes. Unicef is a major player among organisations working to improve the outlook for babies and young children. Its four-part strategy centres on prevention, counselling, testing/medication and support [21] (Panel 4).



**Panel 4: Unicef priorities for prevention among infants and young children [21]**

- Primary prevention of HIV among women of reproductive age, before they get pregnant, within services related to reproductive health and other health and HIV service delivery points, including working with community structures.
- Appropriate counselling and support to women living with HIV to enable them to make an informed decision about their future reproductive life, with special attention to preventing unintended pregnancies.
- For pregnant women living with HIV, readily available testing and access to the antiretroviral drugs that will help mothers' own health and prevent infection being passed on to their babies during pregnancy, delivery and breastfeeding.
- Better integration of HIV care, treatment and support for women found to be positive, and their families.

## Conclusion

Real excitement may be justified by the Mississippi discovery but the practical application of such a prevention strategy seems a long way off. In the context of the developing world, the priority still seems to lie in making antenatal testing available and then ensuring access to and uptake of HAART as prevention strategy. However, one could equally argue that, worldwide thus far, we have yet to prevent PMTCT effectively using these methods. Therefore, where the availability of lifelong treatment is uncertain at best, perhaps a 'functional cure' (with HAART used as in the Mississippi case and exempting pregnant mothers from ART pre delivery), could in fact be a useful approach.

The overall message has to be that, while these published findings are promising, it would be unwise to offer false reassurance at this stage. For now, we still need people to keep on using condoms, get tested, and to start and stay on effective treatment – as researchers continue to explore this alternative and exciting prevention strategy.

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## Further reading

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